University of Alberta

Family Caregiver Needs Just Prior to the Cancer Patient's Hospice Admission to Die

by

Jacqueline Ruby Peden

A thesis submitted to the Faculty of Graduate Studies and Research

in partial fulfillment of the requirements for the degree of

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Jacqueline Peden

12260 St. Albert Trail

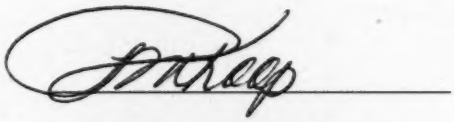
Edmonton, Alberta, T5L 4G6

October 2, 1998

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Family Caregiver Needs Just Prior to the Cancer Patient's Hospice Admission to Die submitted by Jacqueline Ruby Peden in partial fulfillment of the requirements for the degree of Master of Nursing.



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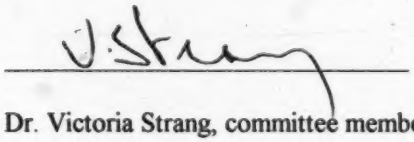

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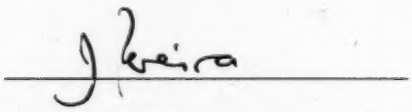

Dr. Jose Pereira, committee member

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Date of Approval

Abstract

The purpose of this descriptive quantitative study was to identify the needs of family caregivers just prior to the cancer patient's admission to a hospice to die. Twenty-one family caregivers whose cancer patient had been admitted to one of 3 palliative care units, identified needs in terms of importance and the degree to which these needs were met.

The average respondent was female, 58 years of age, and in good health. Information, Patient Care, and Spiritual were the top three need categories identified. The need for "adequate sleep" was identified as a barrier to providing care in the home.

Identification of caregiving needs during the end stage of the patient's life will facilitate the determination and provision of services. This would allow the cancer patient to stay at home as long as possible, including a home death if desired.

Dedicated to

Randy and Neil

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Introduction

The following is a paper format thesis comprised of three chapters. The introductory chapter is a summary of the research project including the theoretical framework, background, purpose, literature review, and method. Additional details pertaining to the sample, data collection, data analysis, results, study limitations, implications for practice, and future research can be found in the paper, **Family Caregiver Needs Just Prior to the Cancer Patients Hospice Admission to Die.** This paper, which is the second chapter of the thesis, identifies the common needs, need categories, and needs that were not satisfied just prior to the hospice admission of the cancer patient who had been cared for in the home by family caregivers in the study. Common characteristics of these family caregivers will also be discussed. In the final chapter additional information will be provided about the study findings, limitations, and future research not already discussed in the article.

Background

In 1998, in Canada an estimated 129,200 new cases of cancer will be diagnosed and 62,700 deaths will occur (National Cancer Institute of Canada, 1998). An increase in the incidence of cancer and an equally dramatic rise in cancer related mortality is projected for the year 2000 (Scott, 1992). This increase in cancer related deaths will affect the delivery of palliative care. The current trend of shifting resources from hospital to home and the closure of hospital beds means that more cancer patients will receive care in the home. Given the increase of the incidence of cancer and the related increase in mortality, with the shift of resources to the home, the burden of caring for the increasing

numbers of patients with advanced cancer, with some assistance from home care programs is becoming the family's responsibility.

Purpose

The purpose of this study was to identify the needs of family caregivers who decide they can no longer manage the care of the cancer patient at home. The research question was:

What are the needs of family caregivers just prior to the cancer patients admission to a hospice to die?

Definition of Terms

Needs were defined as circumstances requiring some course of action. The **family caregiver** was the family member or friend who was the most responsible for meeting the daily physical and emotional needs of the patient before hospice admission. A **hospice** was defined as a continuing care facility with a unit which was designated to provide palliative care to cancer patients.

Theoretical Framework

The theoretical framework for this research was based on Betty Neuman's Systems Model. According to this model a person or system and the environment have a reciprocal relationship which involves the system's adjustment to stressors produced within the environment (Russell, Hileman, & Grant, 1995). The system's focus is to adjust to the feedback input from the environment and maintain or retain balance that is perceived as acceptable by the system (Russell, Hileman, & Grant, 1995).

The person or system is defined as the family caregiver and the advanced cancer patient who needs care. The environment is broadly defined as factors internal and

external surrounding the system at any given time (Russell, Hileman, & Grant, 1995). For the purposes of this study, the internal environment is composed of the family caregiver and the advanced cancer patient while the external environment exists outside of this system. Stressors produced within the environment are classified into three different categories (Cross, 1985). Intrapersonal stressors occur within the individual, for example, the caregivers anger with the patient's diagnosis of terminal cancer. Interpersonal stressors occur between one or more individuals. An example of interpersonal stressors might be the expectations that the patient has of the family caregiver in the caregiving role. Extrapersonal stressors, such as, the demands of the family caregiver's employer are forces occurring outside the system.

In this study, the stressors occurred when the family caregiver was providing care to the patient with advanced cancer in the home. An example of family caregiver stressors are the identified needs which were important to the caregivers but were not being met to the caregivers satisfaction. The Home Caregiver Need Survey, the tool used to assess the needs of family caregivers, was developed from the framework of Neuman's System Model.

Literature Review

Early in the terminal phase of the illness, the majority of cancer patients and their family caregivers indicate a preference for home care over hospital or an institution (Brown, Davies, & Martens, 1990; Grobe, Ahmann,& Ilstrup, 1982; Hinton, 1994a). In a qualitative study, eight patients and their families chosen from a home care program and a supportive care program within a regional cancer institute identified factors that determine the choice and success of the home experience (Brown et al., 1990). Home-

based care for advanced cancer patients was likely to be successful if family caregivers were available and able to manage the caregiving responsibilities, if home care services were accessible and available, if the patient was mobile and symptoms were controlled, and if the physical environment of the home was suitable for the mobility of the patient.

Powers and Burger (1987) analyzed data from the American National Hospice Study about the location of palliative care. A major determinant of location of care was the patient's functional status. Patients who were less independent in their performance of activities of daily living were more likely to be cared for in a hospice or hospital rather than at home. This research supports Hinton's (1994a) findings that palliative care in the home is dependent on the stage of the terminal illness. Hinton conducted a study with 77 randomly selected cancer patients and their families from a home care service and reported that 90% of the care of patients with advanced cancer was provided in the home but as the terminal illness progressed, the family caregiver's preference for home care fell from 100% to 45%. These studies suggest that as death approaches, family caregivers no longer believe they are capable of managing the care of the patient in the home.

Research conducted in the past 15 years and in four different countries (Italy, United States, England, and Canada) has revealed home as the place of death 18% to 33% of the time (Costantini et al., 1993; Godkin, Krant, & Doseter, 1983-1984; Hinton, 1994a; McCusker, 1983; McWhinney, Bass, & Orr, 1995). In Canada, 28.1% of 267 patients referred to a palliative home care program died at home (McWhinney et al., 1995). When patients were enrolled in a program aimed at encouraging home deaths, the numbers are considerably higher. Although the percentage of cancer patients who die at home has increased over the past twenty years, the majority of cancer patients still die in

formal health care settings (Flynn & Stewart, 1979; Lubin, 1992; McCusker, 1983; McWhinney et al., 1995).

The preferred location of death and the actual location of death may differ (McWhinney et al., 1995; & Townsend et al., 1990). The patient's preference for a home death (McWhinney et al., 1995) and the degree of family support (De Conno et al., 1996) are two factors associated with home deaths. These findings suggest that the patient and family caregiver must be in agreement for a home death to occur. A random sample of 84 advanced cancer patients selected from a hospital and community setting were interviewed as their disease progressed to determine if their preference for care changed over time (Townsend et al., 1990). Seventy of these 84 patients died during the study and 84% (n=59) of the patients who died gave an initial preference for location of death. Initially 58% (n=34) of these patients wanted to die at home but this decreased to 49% (n=29) at the last interview prior to death. This change in preference was not statistically significant. A majority of the patients who indicated a desire to die at home, died in their chosen location. Sixty-three percent of the patients who died in hospital, however, had stated a preference for death at another location. Thirty caregivers were interviewed after the death of these patients, 70% were satisfied with the location of death but 28% would have preferred a home death. These findings support those from a study which involved the review of charts of 267 patients referred to a palliative home support team, from June 1988 to January 1990 (McWhinney et al., 1995). Although nearly half of these patients had wanted a home death, only 28% achieved this. Therefore, actual numbers of home deaths may significantly underestimate the numbers of patients and family caregivers who would prefer a home death. These findings support the need for research on what

would be needed to accommodate the wishes of patients who want to die at home and the wishes of caregivers who are willing to provide for this.

A majority of informal caregivers of advanced cancer patients are older and in poor health (Hileman & Lackey, 1990; Howell, 1986; Steele & Fitch, 1996a; Steele & Fitch, 1996b). The care of patients with advanced cancer is challenging even for caregivers in excellent health. For caregivers who have health concerns of their own, the responsibilities can be overwhelming. Family caregivers identify managing physical care as the greatest demand (Stetz, 1987; Grobe, Ilstrup, & Ahmann, 1981) and over one-half of family caregivers report significant difficulties in providing physical care at home (Grobe et al. 1981; Holing, 1986)

The two most common reasons for admission to a health care setting prior to death are related to patient symptoms and the inability of the family caregiver to manage care (De Conno et al., 1996; Dunphy & Amesbury, 1990; Hays, 1986; Hinton, 1994b; Lubin, 1992; McWhinney et al., 1995; Soukop & Calman, 1977; Townsend et al., 1990). Soukop and Calman (1977) found that indicators for hospitalization of an advanced cancer patient are the patient's poor adjustment to the terminal disease, an increase in the patient's pain, a decrease in the family caregiver's ability to cope, and a decrease in the patient's activity level. The inability of the family caregiver to manage the patient's care in the home included the difficulty of providing nursing care, the need for respite, family discord, and caregiver illness (Dunphy & Amesbury, 1990; Hinton, 1994b; McWhinney et al., 1995). The responsibilities for home-based caregiving are considerable and many of the caregivers are unable to fulfill these responsibilities on their own.

In a number of studies, family caregivers have identified gaps in the services provided in the home (Jones, Hansford, & Fiske, 1993; Higginson, Wade, & McCarthy, 1990; Hinds, 1985; Mor, Masterson-Allen, Houts, & Siegel, 1992). If advanced cancer patients are to be maintained in the home, services which meet their needs and those of their family caregivers must be provided. Ten to thirty percent of cancer patients and their families report a variety of unmet needs during the course of their terminal illness. These needs range from personal care to household cleaning activities (Hinds, 1985; Mor et al., 1992; Siegel, Raveis, Houts, & Mor, 1991). A random sample of 433 family members of patients who had died of cancer, reported significantly more unmet needs during the terminal period than just after diagnosis (Houts et al., 1988). The most frequently reported unmet need during the terminal period was assistance with the activities of daily living.

Family caregivers have an increased need for services in the terminal stage of the patient's illness (Grobe et al., 1981; Hays, 1986; Houts et al., 1988) such as home visits by physicians, respite, and emotional support (Grobe et al., 1982). The need for palliative services in the home is necessary to increase the chances of a home death (Costantini et al., 1993; Johnson & Oliver, 1991). Even if a home death is preferred, adequate and appropriate home-based palliative services must be provided until care in the home is no longer an option.

The determination of services for family caregivers of dying patients must be based on a thorough assessment of their needs. Considerable research has focused on the identification of needs of family caregivers of persons with cancer during the various stages of cancer and while the patient is being treated or in hospital. There is less research

about the needs of family caregivers who provide care to advanced cancer patients in the home. Family caregiver needs during the final days of the patients life have not been identified, although the hospitalization of patients due to caregiver burden (Dunphy & Amesbury, 1990; Hays, 1986; Hinton, 1994b; Lubin, 1992; McWhinney et al., 1995) suggests that caregiver needs are not being met. With this in mind, a research study was undertaken to identify the needs of family caregivers when they decided it was no longer possible to keep the cancer patient at home.

Method

Research Design and Procedure

A descriptive quantitative approach was used for the study. Ethical approval was obtained from the Health Research Ethics Administration Board (see Appendix A) and administrative approval (see Appendices B-H) from a variety of health agencies in Region 10 in Alberta. This region consists of Edmonton, St. Albert, Sherwood Park, and surrounding area. Family caregivers were accrued from three of the four continuing care facilities, Edmonton General Hospital, Norwood, St. Joseph's Auxiliary Hospital, which have a unit designated to provide palliative care in Region 10.

Admission into one of these continuing care facilities or hospices is arranged by the palliative care consult team from the Regional Palliative Care Program (RPCP). The RPCP consists of four nurses and four physicians with palliative care expertise. This team provides support and consulting services to the region's primary care doctors and nurses in the home and the hospices in Region 10. Two nurses from the RPCP, responsible for arranging admission into a hospice, assisted with recruitment of subjects by following guidelines provided to them (see Appendix I).

Thirty-five of the 42 family caregivers approached by the RPCP nurse agreed to be part of the study. Fourteen of these caregivers decided not to be involved due to the declining health or death of their family member. Arrangements were made to meet the family caregiver either at the hospice or in their home. Five family caregivers from the total sample of 21 caregivers were interviewed 4-12 weeks after the death of the patient because interviews could not be arranged while the patient was on the unit.

An information sheet prepared for the family caregiver (see Appendix J) provided an explanation of the study before an informed consent was signed (see Appendix K). Further information about the study was offered as information was needed.

Instruments

Initially demographic information (see Appendix L) was obtained and then before completing the Health Caregiver Need Survey (HCNS) (see Appendix M) the caregiver was asked to recall the time period when the decision to admit the cancer patient to a hospice was made. The caregiver was asked to focus on his or her needs during this time.

The HCNS divides needs into six categories which include: informational needs, household needs, personal care needs, psychological needs, spiritual needs, patient care needs (Hileman, Lackey, & Hassanein, 1992). Informational needs pertain to the knowledge or understanding that can be gained through education or experience. Household needs relate to the management of running a household. Personal care needs pertain to the physical needs of the caregiver, psychological needs to the emotional and relationship needs of the caregiver, and spiritual needs to the caregiver's relationship with a higher being. Patient care needs pertain to providing care to patient.

The HCNS is a 89-item self report survey that asks the participant to rate the importance of their needs on a seven point likert scale. Their satisfaction that these needs were met is also rated on a seven point likert scale.

The HCNS was chosen because the needs of the family caregiver and their needs that were either met or not met can be identified. This tool was developed following a number of studies which identified needs of caregivers who provide care in the home to cancer patients; it only takes 20 minutes to complete; it is based on a theoretical framework; it is comprehensive; and reliability and validity with the target population of the tool has been established.

Reliability and Validity

Construct validity and internal consistency reliability of the HCNS has been established by principle factor analysis and Cronbach's alpha coefficient. The six need categories were clearly described by principle factor analysis with promax rotation during the analysis of a study which used the HCNS with 392 caregivers of cancer patients at home (Hileman et al., 1992). The internal consistency of each factor and item was analyzed by calculating Cronbach's alpha coefficient. Dimension coefficients ranged from 0.88 to 0.96 in the six need categories and a Coefficient Theta of 0.98 was calculated to evaluate the overall reliability of all items in the six factors (Hileman et al., 1992).

Permission to use the HCNS was obtained from Dr. J.W. Hileman (see Appendix N). Five one word changes were made with the instrument so the new "generisized" HCNS can be used with caregivers of any patient population (J.W. Hileman, personal communication, February 7, 1997). Overall Cronbach alpha of the new HCNS was 0.97 (Hileman, J.W. [1992-1993], identifying the needs of lay home caregivers of patients

with AIDS. (Abstract, J.W. Hileman, personal communication, February 7, 1997). Since the wording in the HCNS will be changed for this study, from "How important is this need for you now?" and "How satisfied is this need for you now?" to "How important was this need for you?" and "How satisfied was this need for you?" permission from Dr. Hileman to use the changed instrument was also obtained (see Appendix O).

Acquiescent response set bias, which is a validity issue, was controlled since the researcher is not connected to palliative home care or the hospices. Also, at the time this study was conducted the terminally ill cancer patient was no longer receiving home care services. Therefore, the family caregiver was not concerned that her or his answers to the HCNS questions would affect the terminally ill patient's home care services. The caregiver was reassured that involvement in the study would not affect care of the patient while in the hospice. The information obtained from this study cannot be generalized to other populations because the sample was not randomly selected.

Scoring

Subjects were asked to rate the importance of need items listed within six separate need categories by using a seven point likert scale ranging from not important to very important in the HCNS. The most important need item within a need category was calculated by summing the subjects rating of each item within a need category and averaging this score. For example, the ratings of the item "Information about medications - effects and schedules" from the Informational needs category was summed and the average score for this item was calculated. When the "Does not apply to me" box was checked this item within the need category was ignored when calculating the average score. The most important need category was calculated by summing the scores of all the

items within a need category and calculating the average score of this category. For example, the sum of the averages of the 14 items within the Informational needs category was calculated and then this score was averaged.

Subjects were also asked to rate how satisfied the need was for them by using a seven point likert scale ranging from not satisfied to very satisfied. Satisfaction and importance scores were used to calculate the barrier needs or those needs that were so urgent that they might constitute a barrier to caregivers providing care (Hassanein, 1988). Caregiver barrier needs of the two groups were calculated using the Hassanein formula: BNS = I [8-S] [BNS = Barrier Need Score, I = Importance Score, and S = Satisfaction Score] (Hileman et al., 1992). The BNS score for each item within a need category was calculated by averaging the sum of responses from each subject within a group. The average BNS of each item within a need category was summed and averaged to determine the need category with the most barrier needs.

Ethical Considerations

Participation in this study was voluntary and subjects were not approached by the researcher until the nurse from the RPCP had obtained their permission. The subjects were advised that they could withdraw from the study at any time and they did not have to answer any question they did not want to answer. Subjects were advised that their family member's hospice care would not be affected if they decided not to participate in the study or if they withdrew from the study.

Anonymity of the subjects was maintained by a coded numbering system so that the subject's names was not attached to the questionnaire or demographic information. A master copy of the numbering system was kept in a locked drawer to which only the

researcher had access. The questionnaires and demographic information was not stored with the master list of the coded numbering system. When the study has been completed the master list will be destroyed but the raw data from this study will be stored separately for seven years according to the policy of the University of Alberta.

Additional details can be found in the paper, **Family Caregiver Needs Just Prior to the Cancer Patients Hospice Admission to Die**.

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Family Caregiver Needs Just Prior to

the Cancer Patient's Hospice Admission to Die

Abstract

Purpose: identify needs of family caregivers who decide they can no longer provide home-based care to cancer patients. **Objective:** identify the most important needs and how well these needs were met just prior to the cancer patient's admission to a hospice to die. **Design:** descriptive quantitative retrospective. **Research question:** What are the needs of family caregivers just prior to the cancer patients admission to a hospice to die? **Setting:** 3 palliative care units in a region which serves patients from urban and rural settings. **Sample:** 21 family caregivers of advanced cancer patients. Caregivers were primarily women aged 37-79 years. **Criteria for selection:** primary family caregiver, 18 years or older and able to read, write, and speak English. **Method:** Needs identified with Home Caregiver Needs Survey, which ranks family caregiver needs in terms of importance and degree to which these needs were met. Demographic questionnaire completed. **Findings:** Most important need categories were Information, Patient Care, and Spiritual. "Adequate sleep" identified as a barrier need. **Conclusions:** Family caregivers need additional information about the type and extent of the patient's disease and how to provide care. They also need greater access to health care professionals, and greater attention to spiritual needs. **Implications for Nursing Practice:** To provide services and support to family caregivers in the home nurses need to assess caregiver needs during the terminal stage of the patient's life. Identified informational needs can assist the nurse plan educational resources for the family.

Introduction

The restructuring of health care services in Canada has resulted in an emphasis on home based care (Grunfeld, Glossop, McDowell, & Danbrook, 1997). Although this has influenced the type and amount of palliative care services available in the home, there is still an expectation that the family be available to provide care for the dying cancer patient. Early in the terminal phase of the illness, the majority of cancer patients and their family caregivers indicate a preference for home care over hospital or an institution (Brown, Davies, & Martens, 1990; Grobe, Ahmann, & Ilstrup, 1982; Hinton, 1994a) and over one-third of patients and their family caregivers indicate a preference for a home death (Hinton, 1994a; McWhinney, Bass, & Orr, 1995; Townsend et al., 1990). The preference for home death may change as the cancer patient deteriorates. Most cancer patients die in a hospital or institution (Hinton, 1994a; McWhinney et al., 1995; Townsend et al., 1990) but a small percentage of family caregivers would have preferred a home death (McWhinney et al., 1995).

Terminally ill patients are usually admitted to hospital because of problems with symptom control or the family caregiver's inability to provide care (De Conno et al., 1996; Dunphy & Amesbury, 1990; Hays, 1986; Hinton, 1994b; Lubin, 1992; McWhinney et al., 1995; Soukop & Calman, 1977; Townsend et al., 1990). Family caregivers report an increased need for services in the terminal stage of the patient's illness (Grobe, Ilustrup, & Ahmann, 1981; Hays, 1986; Houts et al., 1988) and family caregivers have identified gaps in the services provided in the home (Jones, Hansford, & Fiske, 1993; Higginson, Wade, McCarthy, 1990; Hinds, 1985; Mor, Masterson-Allen, Houts, & Siegel, 1992).

Among the many factors associated with home death, the availability of adequate resources seems to be critical for patients who wish to stay home to die (McWhinney et al, 1995). If the health care professional wishes to provide adequate support to the family caregiver during the finals days of the cancer patient's life the needs of the family caregiver must be identified. Although there is nursing research about family caregiver needs during the various stages of the cancer patient's illness, there has been less emphasis on the needs of home-based family caregivers during the terminal phase of cancer. There is no research on the needs of family caregivers who provide care in the home when the patient's death is imminent.

The purpose of this descriptive quantitative study was to identify the needs of family caregivers just prior to the cancer patient's admission to a hospice to die. Needs were defined as circumstances requiring some course of action. The family caregiver was the family member or friend who was most responsible for meeting the daily physical and emotional needs of the patient before hospice admission. A hospice was defined as a palliative care unit within a continuing care facility, designated to provide palliative care to cancer patients.

Literature Review

Research conducted in the past 15 years and in four different countries (Italy, United States, England and Canada) has revealed home as the place of death 18% to 33% of the time (Costantini et al., 1993; Godkin, Krant, & Doster, 1983-1984; Hinton, 1994a; McCusker, 1983; McWhinney et al., 1995). The percentage of cancer patients who die at home has been increasing over the past twenty years but the majority of cancer patients

still die in formal health care settings (Flynn & Stewart, 1979; Lubin, 1992; McCusker, 1983; McWhinney et al., 1995).

Although the majority of family caregivers indicate a preference for home care over hospital or an institution (Brown et al., 1990; Grobe et al., 1982; Hinton, 1994a) studies suggest that as death approaches and the patient's functional status deteriorates family caregivers no longer believe they are capable of managing a home death (Hinton, 1994a; Powers & Burger, 1987). Ten to 34% of cancer patients who are admitted to a hospital or hospice, die within one week of admission (Boyd, 1993; Hinton, 1994b; McWhinney et al., 1995; Soukop & Calman, 1977). Ten to 18% of patients admitted to hospital, died within 48 hours of admission (Boyd, 1993; Hinton, 1994b) and 13% to 34% died within two to fours days of admission (McWhinney et al., 1995; Soukop & Calman, 1977). The mean length of stay for the final admission to hospital or hospice was not indicated in these studies. Reasons for admission of these patients are either related to uncontrolled physical symptoms or family caregiver fatigue and inability to cope (Boyd, 1993; Hays, 1986; Hinton, 1994b; Lichter & Hunt, 1990).

During their last month of life, patients commonly report problems with activities of daily living (Houts et al., 1988). Similarly, Stetz (1987), reported that during the terminal stage of cancer, 69% of a sample of 65 home-based family caregivers identified managing physical care as the greatest demand. Family caregivers have identified an increased need for home visits by physicians, respite, and emotional support during the terminal stage of the patient's illness (Grobe et al., 1982), and the availability of palliative services in the home is necessary to increase the chances of a home death (Costantini et

al., 1993; Johnson & Oliver, 1991). The likelihood of a home death increases with the number and intensity of nursing visits (Bass et al., 1984; McWhinney et al., 1995).

If the advanced cancer patient is to be maintained in the home, services which meet the needs of patients and family caregivers must be provided. Ten to thirty percent of terminally ill cancer patients and their families report a variety of unmet need, ranging from personal care activities to household cleaning activities (Hinds, 1985; Mor et al., 1992; Siegel, Raveis, Houts, & Mor, 1991). A random sample of 433 family members of patients, who had died of cancer, reported significantly more unmet needs during the terminal period than just after diagnosis (Houts et al., 1988). The most frequently reported unmet need during the terminal period was assistance with the activities of daily living.

The determination of services needed for family caregivers of dying patients must be based on a thorough assessment of their needs. Family caregiver needs during the final days of the patients life have not been identified, although the hospitalization of patients due to care giver burden (Dunphy & Amesbury, 1990; Hays, 1986; Hinton, 1994b; Lubin, 1992; McWhinney et al., 1995) suggests that caregiver needs are not being met.

Method

Setting and Sample

Within the region where the study was conducted, palliative patients receive professional and support services in the home from the Home Care program and medical care from the family physician. If the palliative patient is acutely ill and medical care cannot be provided in the home, hospitalization or admission into the acute palliative unit is arranged. If the advanced cancer patient is too stable to require hospitalization but the

family caregiver cannot manage care at home, admission to a continuing care facility with designated palliative care beds is arranged. There are 56 beds in four continuing care facilities designated to provide palliative care for people who live in this region.

Admission into one of these facilities or hospices is arranged by the palliative care consult team from the Regional Palliative Care Program (RPCP), which consists of four nurses and four physicians with palliative care training. This team provides support and consulting services to the region's primary care doctors and nurses in the home and the hospices. Palliative patients can be admitted to a hospice from the home, hospital, or the acute palliative care unit. Admission to a hospice from home usually means the cancer patient is not acutely ill and requiring hospitalization but that the patient may be experiencing symptoms that are difficult to manage or requiring care that the family caregiver can no provide.

To be included in this study the primary family caregiver had to be 18 years or older and able to read, write, and speak English. The advanced cancer patient of the family caregiver had to be admitted into the hospice from home.

Instruments

The Health Caregiver Need Survey (HCNS), developed from three descriptive studies conducted to identify the needs of family caregivers of home-based cancer patients was used (Hileman, Lackey, & Hassanein, 1992). Needs pertaining to information, household, personal care, psychological, spiritual, and patient care are organized into six categories. This 89-item self report survey is arranged into two seven point likert scales that measure the importance and satisfaction of needs. The responses range from "very important" to "not important" and "very satisfied" to "not satisfied". For

this study, the wording in the HCNS was changed from "How important is this need for you now?" and "How satisfied is this need for you now?" to "How important was this need for you?" and "How satisfied was this need for you?".

Construct validity and internal consistency reliability of the HCNS has been established by principle factor analysis and Cronbach's alpha coefficient. The six need categories were clearly described by principle factor analysis with promax rotation. The internal consistency of each factor and item was analyzed by calculating Cronbach's alpha coefficient. Dimension coefficients ranged from 0.88 to 0.96 in the six need categories and a Coefficient Theta of 0.98 was calculated to determine the overall reliability of all items in the six factors (Hileman et al., 1992). Five one-word changes were made with the instrument so the new "generisized" HCNS can be used with caregivers of any patient population. Overall Cronbach alpha of the new HCNS was 0.97 (J.W. Hileman, personal communication, February 7, 1997) in a population of caregivers of AIDS patients.

Demographic information about the patient and family caregiver as well as whether a home death was desired, and reason for hospice admission was also obtained.

Procedure

Following ethical and administrative approval, two nurses from the RPCP responsible for arranging admission into a hospice, identified family caregivers who were willing to be in the study. The researcher arranged to meet the family caregivers at the location of their choice, and following an explanation of the study, and an explanation of ethical considerations an informed consent was signed.

Before completing the HCNS the caregiver was asked to recall the time period when the decision to admit the cancer patient to a hospice was made. The caregiver was asked to focus on his or her needs during this time.

Data Analysis

Data was analyzed using content and descriptive analysis techniques to identify factors which may have influenced the family caregivers' decision to have the cancer patient admitted to a hospice; to describe the common characteristics of the family caregiver who was unable to manage a home death; and to identify family caregiver needs that were important but not met in the community. Demographic data were analyzed, using measures of centrality (mean, mode, and median) and dispersion (range, ratio, and standard deviation) as appropriate.

The mean importance and barrier need scores of the top ten items from the HCNS were ranked in order of importance. The mean importance scores of the six need categories from the HCNS were also ranked in order of importance. Caregiver barrier needs of the two groups were calculated, using the Hassanein formula: BNS = I [8-S] [BNS = Barrier Need Score, I = Importance Score, and S = Satisfaction Score] (Hileman et al., 1992). Mean BNS scores were calculated for each individual need as well as for need categories. These scores were ranked to determine the barrier needs.

Results

Sample

The sample consisted of 21 family caregivers of 42 patients consecutively admitted to hospice from home or through an emergency department. Nurses from the RPCP approached eligible family caregivers of patients. Seven of the 42 caregivers

refused to be part of the study and 14 caregivers who initially stated an interest, withdrew prior to the interview due to the patient's imminent death. Five family caregivers from the total sample were interviewed 4-12 weeks after the death of the patient because interviews could not be arranged while the patient was on the unit. The data from these 5 family caregivers were compared with those from 17 caregivers who were interviewed prior to the patient's death. No significant differences were found. Thus, the data were grouped and analyzed together.

Patient and Family Caregiver Characteristics

Patients ranged in age from 39 to 91 years old with a mean age of 73.6 ± 14.2. Ten patients were female and 11 patients (52.4%) were male. Table 2-1 summarizes the characteristics of the patients. Eighteen (85.7%) of caregivers were women between 37 and 79 years old, with a mean age of 58.0 ±11.0. Nine (42.9%) of the female caregivers were daughters or daughter-in-laws. Thirteen (61.9%) of the caregivers were the patients' sole caregiver. Table 2-2 summarizes the characteristics of the family caregivers.

Factors Related to Caregiving Experience

Length of illness ranged from 6-182 weeks with 8 (38%) of patients ill $\leq$ 24 weeks. Length of time as a caregiver ranged from 2-130 weeks with 15 (71.4%) patients cared for $\leq$ 24 weeks. Five patients had moved in with the caregiver who was either a daughter or sister. Two daughters moved home to care for the patient. Most patients 19 (90.4%) had received home care services. Eleven patients (52.4%) had received a combination of professional and personal care services and 6 (28.6%) had received professional services only.

Factors Related to Hospice Admission

The male caregivers did not want a home death due to the physical care of the patient. Only 2 caregivers, who were wives of the patient, wanted a home death although their husbands wanted hospice admission. Three caregivers, who did not want a home death due to the physical care demands, had received only professional services from home care. Table 2-3 summarizes factors related to the patient and caregivers preference for hospice death.

Family Caregiver's Needs

The mean importance scores of the six need categories in rank order of importance are information, patient care, spiritual, personal care, psychological, and household. The top 10 important needs are listed in Table 2-4 in mean rank order of importance with the satisfaction mean, and barrier score mean of these needs. The top 3 important needs in each category are listed in Table 2-5 in mean rank order of importance with the satisfaction mean, and barrier score mean of these needs .

There was one need that was considered a barrier according to the Hassanein (1988) definition (a score $\geq$ 25). From the personal care category the need "Adequate sleep" had a barrier score of 26.7. The next highest barrier scores were "Information about what to expect in the future" (barrier score of 21.6) and "Time to rest" (with a score of 17.9).

Discussion

The Family Caregiver

Although family caregivers' perceptions of the demands of the care giving role can change after the death of the patient (Stetz & Hanson 1992; Holing, 1986) the

important needs identified by the 5 caregivers after the death of the patient were not significantly different from the needs of the caregivers interviewed before the death of the patient. Since the caregivers were asked to identify their needs prior to hospice admission, all caregivers identified needs retrospectively and for the same time period. It was noticed, however, that caregivers interviewed before the death of the patient found it more difficult to focus on their needs prior to hospice admission and needed reminders to do so. Caregivers interviewed after the death of the patient, however, seemed to find it easier to identify their needs before hospice admission. They were also not as stressed. These findings suggest that post-death interviews have advantages over interviews which take place when death is imminent.

Common characteristics of the family caregivers in this study are similar to those found in the literature except for the high percentage of daughters and daughter-in-laws. Most caregivers are spouses of the terminally ill cancer patient (Hileman et al., 1992; Holing, 1986; Longman, Atwood, Sherman, Benedict, & Shang, 1992; McMillan, 1996; McMillan & Mahon, 1994; Nugent, 1988; Steele & Fitch, 1996a). Other studies indicate that the majority of family caregivers of patients with advanced cancer are between the ages of 50 and 79 (Hileman & Lackey, 1990; McMillan, 1996; Nugent, 1988; Skorupka & Bohnet, 1982; Steele & Fitch, 1996a; Steele & Fitch, 1996b). More than 50% of family caregivers rate their health as good to poor, and few rate their health as excellent (Hileman et al., 1992; Howell, 1986; Steele & Fitch, 1996a; Townsend et al., 1990; Wingate & Lackey, 1989).

Factors Related to Hospice Admission

The characteristics of family caregivers who keep cancer patients at home to die are not identified in the research literature but characteristics of patients who die at home are identified. The most common characteristic of patients who die at home is that they are married (Dunphy & Amesbury, 1990; Costantini et al.,1993; Mor & Hiris, 1983; Powers & Burger, 1987). According to McWhinney et al. (1995), a significant number of these patients also have a family member other than the spouse assisting with care. Although the marital status was not collected for the patients in this study, daughters or daughter-in-laws were the primary caregiver for almost one-half of the patients. A majority of caregivers (61.9%) did not have other family members assisting with the care.

A higher education and income (McCusker, 1983; Mor & Hiris, 1983), and a longer length of time between diagnosis and death are other factors associated with a home death (McCusker, 1983; Powers & Burger, 1987). The education of the patient was not known but most had a low income. Although some of the patients had been ill for over 2 years, the majority were ill for less than one year and about 1/3 for less than 3 months. These findings suggest that patients who are admitted to a hospice unit to die have different demographic characteristics than those of patients who die at home.

Although, the preferred location of death and the actual location of death may differ (McWhinney et al., 1995; & Townsend et al., 1990), the patient's preference for a home death (McWhinney et al., 1995) and the degree of family support (De Conno et al., 1996) are associated with home deaths. These findings suggest that the patient and family caregiver must be in agreement for a home death to occur. In this study there was no

agreement between the patient and caregiver about a home death and 5 caregivers had not discussed this option with their patient.

The two most common reasons for the patient's hospice admission prior to death in this study were related to physical symptoms of the patient or the physical care of the patient and these findings are supported in the literature (De Conno et al., 1996; Dunphy & Amesbury, 1990; Hays, 1986; Hinton, 1994b; Lubin, 1992; McWhinney et al., 1995; Soukop & Calman, 1977; Townsend et al., 1990). A significant finding in this study was that "adequate sleep" was identified as a barrier need. This means that the need for adequate sleep was so urgent that this need may have constituted a barrier for caregivers in providing care at home. Although "time to rest" by definition is not a barrier, that is the score was not >25, this need was identified third highest among barrier need scores. Fatigue, nervousness, and anxiety increase for caregivers during the patient's final days (Hays, 1986; Hinton, 1994a; Howell, 1986; Jensen & Given, 1991; Willert, Beckwith, Holm, & Beckwith, 1995). Many caregivers who become fatigued are not sufficiently relieved while the patient remains at home (Hinton, 1996). These findings suggest that premature hospice admissions may occur if support for caregiver rest is not provided.

The majority of patients (n=13; 61.8%) in this study died within 30 days of hospice admission and 4 patients (19%) died within 7 days. Other research has found that a small percentage of cancer patients who are admitted to a hospital or hospice and die within one week of admission (Boyd, 1993; Hinton, 1994b; McWhinney et al., 1995; Soukop & Calman, 1977). Little is known about whether these results indicate success of palliative home care. For patients and family caregivers who wanted a home death, the admission to hospice may have been seen as a failure. The provision of more services

might have allowed them to die at home. For other patients and family caregivers, the hospice admissions may have been timely.

Family Caregiver's Needs

Informational and psychological needs have been identified as the top two need categories for family caregivers who keep terminally ill patients at home (Hileman & Lackey, 1990; Hileman et al., 1992; Wingate & Lackey, 1989). Although information was the most important need category in this study patient care needs were second and psychological needs rated as fifth for importance.

Patient care needs may be more important in this population as the caregiver was usually the daughter or daughter-in-law who did not live with the patient and was the only family caregiver. Also during their last month of life patients commonly report problems with activities of daily living (Hinton, 1986; Houts et al., 1988) and caregivers identify managing physical care as the greatest demand (Stetz, 1987).

Family caregivers have stated that the least helpful nursing behavior is nurses providing emotional support to them instead of providing physical and psychosocial care to the patient (Lewandowski & Jones, 1988; McGinnis, 1986; Ryan, 1992; Skorupka & Bohnet,1982). This may explain why psychological needs were not considered as important as patient care needs in this study. It is important to note, however, that "information about what to expect in the future", a need found in the psychological need category, was the second highest barrier need score. Family caregivers need information to help them prepare for upcoming patient care issues.

Even though some subjects scored the needs in this category as "does not apply", spiritual needs ranked as the second most important category. Although this ranking was

also found in a comparison study between the needs of caregivers of clinic and hospice patients (Harrington, Lackey, & Gates, 1996) spiritual needs have not been identified as important in other studies in the literature. Because the caregivers in this study were caring for patients in the final stage of life, spirituality may have been a key issue in preparing for death.

Needs which were deemed as important by the family caregivers in this study focused on information about the patient's health, factors which relate to the care of the patient, and available resources. These needs have been identified in numerous other studies as well (Decker & Young, 1991; Hampe, 1975; Harrington et al., 1996; Hileman & Lackey, 1990; Hileman et al., 1992; Hinds, 1985; Longman et al., 1992; McGinnis, 1986; Stetz & Hanson 1992; Tringali, 1986; Wingate & Lackey 1989; Wright & Dyck, 1984). The importance of access to physicians and home visits by professionals, especially in the terminal stage of the illness are important needs identified in this study and supported in the literature (Grobe et al., 1982).

Study Limitations

The sample size of this study is small and results must be interpreted cautiously as a result. Since the sample was not randomly selected, results cannot be generalized to the total population. The family caregivers who declined to be part of the study may have had views which differ from those of the participants. This also threatens the validity of this study.

External validity is also a concern as the study was retrospective. The subjects were reminded during the interview to identify their needs prior to hospice admission but

the participants whose patient was still alive seemed to have greater difficulty with this due to their concern with their needs at that time.

Demographic information, such as, the patient's marital status and the caregiver's work status as well as an indication of changes to home care services prior to hospice admission may have provided a clearer picture of the caregiver and patient who decide on hospice admission.

Implications for Practice

Needs of the family caregiver change throughout the trajectory of the cancer patient's illness. Since information is an important need of family caregivers with advanced cancer and information needs will be different during the terminal phase, the nurse needs to be sensitive to these needs. The development of information packages specific to the needs of family caregivers during the terminal phase of the patient's illness and information about how to care for the advanced cancer patient in the home is important. Nurses in the home should be aware of the spiritual practices of the advanced cancer patient and family caregiver and encourage this type of support when appropriate.

Future Research

A longitudinal study about the needs of family caregivers in the home during the trajectory of the cancer patient's illness would not only provide insight into caregiver needs at different times during the cancer patient's illness but would also help to identify caregiver needs in the final days of the patient's life.

A comparison of the needs and unmet needs of family caregivers who keep the cancer patient at home to die with family caregivers who do not, would also provide additional information in this area. Finally, exploring the needs of family caregivers with

different characteristics, such as different cultural backgrounds, gender, and age would enrich the knowledge of health care professionals who provide in the home.

Conclusion

The identification of caregiver needs during the end stage of the patient's life will facilitate the determination and provision of services which would allow the cancer patient to stay at home as long as possible. Meeting the needs of the family caregiver at this time may also maintain the well-being of the caregiver. The identification of family caregiver needs is crucial not only to the well-being of the caregiver but to the patient as well, since the emotional and physical health of the family caregiver directly impacts the care of the terminally ill cancer patient.

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Table 2-1

Characteristics of the Patient

Characteristics	Frequency (n=21)	Percent
Gender		
Female	10	47.6
Male	11	52.4
Patient Age		
37-50 years	1	4.8
51-65 years	4	19.0
66-79 years	5	42.9
80-91	7	33.3
Income*		
<$10,000	1	4.8
$10,100-$20,000	5	23.8
$20,100-$30,000	8	38.1
$30,100-$40,000	1	4.8
$40,100-$50,000	3	14.3
>$50,000	2	9.5
Length of Time Ill*		
1-12 weeks	4	19.0
13-24 weeks	4	19.0
25-52 weeks	6	28.6
53-104 weeks	2	9.5
105-156 weeks	4	19.0
157-208 weeks	1	4.8
Length of Hospice Stay*		
1-7 days	4	19.0
8-14 days	2	9.5
15-30 days	7	33.3
31-60 days	4	19.0
61-90 days	1	4.8
91-120 days	1	4.8
missing*	2	9.5

* Income: if the patient is married the income was combined with the spouse. (n=20)
* Length of time ill: from diagnosis to admission into hospice.
* Length of hospice stay: from admission to death.
* missing: patients still alive.

Table 2-2

Characteristics of the Family Caregiver

Characteristics	Frequency (n=21)	Percent
Gender		
Female	18	85.7
Male	3	14.3
Caregiver Age		
37-50 years	5	23.8
51-65 years	11	52.4
66-79 years	5	23.8
Relationship to Patient		
Wife	6	28.6
Husband	2	9.5
Sister	2	9.5
Daughter	8	38.1
Son	1	4.8
Daughter-in-law	1	4.8
Girlfriend	1	4.8
Education		
< Grade 12	5	23.8
Grade 12	10	47.6
> Grade 12	6	28.6
Health		
Poor	1	4.8
Fair	7	33.3
Good	12	57.1
Excellent	1	4.8
Only Caregiver		
Yes	13	61.9
No	8	38.1

Table 2-3

Factors Related to Preference for Hospice Death

Factors	Caregiver	Patient*
Prefer Home Death		
Yes	n=2 (9.5%)	n=3 (14.3%)
No	n=18 (85.7%)	n=13(61.9%)
Not considered	n=1 (4.8%)	n=5 (23.8%)
Reason For Preference Of No Home Death		
Physical care of patient	n=8 (38.1%)	n=3 (14.3%)
Psychological concern	n=6 (28.6%)	n=5 (23.8%)
Desire for hospice admission	n=1 (4.8%)	n=6 (28.6%)
No caregiver in home	n=4 (19.0%)	n=1 (4.8%)
No answer given	n=2 (9.5%)	n=6 (28.6%)
Reason For Hospice Admission		
Physical care of patient	n=6 (28.6%)	
Physical symptoms of patient	n=11 (52.4%)	
Psychological needs	n=1 (4.8%)	
Want hospice care	n=2 (9.5%)	
No caregiver in home	n=1 (4.8%)	

* Information about patient preferences was provided by the family caregiver.

Table 2-4

Top 10 Important Needs
(In rank order of mean with corresponding satisfied and barrier score mean)

Needs	Importance	Satisfied	Barrier
trusting relationship with patient	6.95	6.76	8.57
information: type, extent of disease	6.90	6.10	13.14
access to doctor	6.86	5.67	15.76
ways to keep patient comfortable	6.76	5.90	14.29
information: symptoms to expect	6.71	5.52	16.62
honest updated information	6.60	6.20	11.05
ways to encourage patient	6.57	5.81	14.57
support from my family	6.45	6.30	11.15
home visits by professionals	6.38	5.05	16.67
someone to talk to	6.35	6.15	10.45

(Need value 6 = very important, 7 = extremely important)
(Satisfied value 5 = fairly satisfied, 6 = a little satisfied, 7 = not satisfied)
(Barrier Need > 25 = > than moderate in importance + > than moderate in dissatisfaction)

Table 2-5

Top 3 Important Needs in Each Category
(In rank order of mean with corresponding satisfied and barrier score mean)

Needs Category	Importance	Satisfied	Barrier Score
Informational			
trusting relationship with patient	6.95	6.76	8.57
information: type, extent of disease	6.90	6.10	13.14
access to doctor	6.86	5.67	15.76
Patient Care			
ways to keep patient comfortable	6.76	5.90	14.29
home visits by professionals	6.38	5.05	16.67
ways to provide adequate nutrition	6.10	5.81	11.67
Spiritual Care			
prayers from others	5.80	6.15	8.35
strong faith in God	5.50	6.00	7.00
hope for future	5.45	4.95	16.26
Personal Care			
support from my family	6.45	6.30	11.15
someone to talk to	6.35	6.15	10.45
caring and interested professionals	6.25	5.63	12.84
Psychological			
ways to encourage patient	6.57	5.81	14.57
information about hospice	6.48	5.71	13.05
ways to maintain family life	4.95	5.33	9.19
Household			
caregiver hotline	4.95	4.90	7.95
non-professional help physical care	4.63	5.37	8.53
help with errands	4.33	4.95	11.52

(Need value 4 = important, 5 = quite important, 6 = very important, 7 = extremely important)
(Satisfied value 3 = quite satisfied, 4 = satisfied, 5 = fairly satisfied, 6 = a little satisfied, 7 = not satisfied)
(Barrier Need > 25 = > than moderate in importance + > than moderate in dissatisfaction)

Conclusion

Discussion of Findings

Information about the family caregivers and their needs that was compiled from the results of the study but not mentioned in the previous article will be discussed. The ratio of first and second generation caregivers was approximately equal. Ten first generation caregivers which include wives, husbands, and sisters and 11 second generation caregivers which include daughters, a daughter-in-law, a son, and a girlfriend were identified. Whether the important needs or need categories of these caregivers would be different has yet to be addressed. Would there be differences between the specific informational needs identified by these two groups of caregivers due to the exposure that the second generation caregivers may have to technology such as the Internet? Would the spiritual need category be more important for family caregivers in the first generation because of their age?

According to 1998 Canadian Cancer Statistics men outnumber woman for new cases and deaths but the proportion of men and woman patients in this study was approximately equal (National Cancer Institute of Canada, 1998). Also according to the statistics, common cancers are prostate, lung, breast, and colorectal but in this study no one had a diagnosis of breast cancer and 5 (23.8%) of patients had pancreatic cancer. Eight (38%) of patients were ill for 6 months and only 3 (14.3%) were ill longer than one year. A longer length of time between diagnosis and death are factors associated with home death (McCusker, 1983; Powers & Burger, 1987). The survival time of patients with pancreatic and lung cancers is shorter than patients with prostate and breast cancer. This suggests that the family caregiver and cancer patient with a shorter prognosis may

not have the time to prepare for a home death and may decide on a hospice admission as a result.

Four (19.0%) patients admitted to the hospice died within 7 days and 13 (61.8%) of patients admitted to hospice died within 30 days. Hays (1986) found that most of the subjects she studied either died at home or were at home until the last week before death. Other research studies also found that a small percentage of cancer patients who are admitted to a hospital or hospice and die within one week of admission (Boyd, 1993; Hinton, 1994; McWhinney, Bass, & Orr, 1995; Soukop & Calman, 1977). Ten to 18% of patients admitted to hospital died within 48 hours of admission (Boyd, 1993; Hinton, 1994) and 13% to 34% died within two to four days of admission (McWhinney et al., 1995; Soukop & Calman, 1977).

Reason for admission of the patients who died within 30 days of hospice admission was either the physical care or physical symptoms of the patient. According to the literature, reasons for admission of these patients are either related to uncontrolled physical symptoms or family caregiver fatigue and inability to cope (Boyd, 1993; Hays, 1986; Hinton, 1994; Lichter & Hunt, 1990). Hays (1986) suggests that patients and families require a higher intensity of care during the final days of life. The final days can be a crucial testing time for caregivers who wish to keep a family member at home to die (McWhinney et al., 1995). Whether an increase of caregiver support during the last days of the patient life would prevent these admissions is not known.

Study Limitations

The sample size of this study is small and results must be interpreted cautiously as a result. A larger sample size would have been preferable but difficulties with accrual

were encountered. Caregivers were not approached until 7 days after admission. This decision was made in order to avoid intrusion at a most stressful period. A number of patients admitted into the hospice deteriorated rapidly and died within a few days of admission. These caregivers were lost to the study. Some of the family caregivers who had agreed to be part of the study declined when approached by the researcher due to the patient's impending death. The time period just prior to the patient's actual hospice admission and the time period just after hospice admission are stressful for the family caregiver and deciding on the best time to approach family caregivers was difficult. Accrual may have been easier if the family caregiver had been approached during the bereavement follow-up visit.

Five family caregivers from the total sample were interviewed 4-12 weeks after the death of the patient because interviews could not be arranged while the patient was on the unit. Caregivers from both groups identified their needs retrospectively and the group of caregivers interviewed after the death appeared more relaxed and did not seem to have any difficulties responding to the questions. The most important needs in all categories from the two groups were compared and no significant difference was found. As a result, the data from these caregivers were analyzed along with the data from the remaining family caregivers.

The information about the cancer patient's diagnosis, reason for hospice admission, and home care services was provided by the family caregiver. Since this information came only from the perspective of the caregiver there may be a lack of details which would be pertinent. A chart review to confirm this information may have added insight into the family caregiver's perception of this type of information. It may have been

useful to determine which home care services had been received and whether or not they had been increased prior to the cancer patient's hospice admission. Family caregivers have identified an increased need for home visits by physicians, respite, and emotional support during the terminal stage of the patient's illness (Grobe, Ahmann, & Ilstrup, 1982), and the likelihood of a home death increases with the number and intensity of nursing visits (Bass et al., 1984; McWhinney et al., 1995).

Implications for Practice

Information from this study may help health care professionals identify the resources and services which would assist family caregivers keep advanced cancer patients at home to die in this region. Since adequate rest was a barrier need, support services during the end stage which would allow the caregiver adequate rest is important. Identified informational needs can assist the health care professional plan educational resources for the family. An awareness of the importance of increased nursing visits and access to physicians during the terminal stage of the illness is useful in planning support. The importance of an ongoing assessment of the family caregiver's needs during the trajectory of the patient's illness so that needs can be met before a crisis occurs may also assist family caregivers keep their patient at home longer.

Future Research

Determining the needs of the family caregivers during the final days of the cancer patient's life would allow home care agencies to plan care that would maximize the likelihood of home-based deaths for patients who desire them. A longitudinal study about the needs of family caregivers in the home during the trajectory of the cancer patient's illness would not only provide insight into caregiver needs at different times during the

cancer patient's illness but would also help to identify the degree to which caregiver needs in the final days of the patient's life compare with prior needs.

Further research should focus on family caregivers who keep the cancer patient at home to die with family caregivers whose patient is admitted to a hospital or hospice. Exploration of patient illness characteristics, family caregiver needs, and the services provided to these families would allow us to determine how these two client groups differ. Perhaps the findings would provide us with greater direction in the provision of care which would allow more patients to remain in their homes during the final phase of life. Finally, exploring the needs of family caregivers with different characteristics, such as different cultural backgrounds, gender, and age would enrich the knowledge of health care professionals who provide care in the home and would facilitate care which is tailored to the needs of patients.

Conclusion

This research study identified family caregiver needs that were important but not met in the community, common characteristics of the family caregiver who was unable to manage a home death, and factors which may have influenced the family caregivers decision to have the cancer patient admitted to a hospice.

If advanced cancer patients are to be maintained in the home, services which meet the needs of patients and family caregivers must be provided. Although there has been an increase in services provided in the home by home care programs in Alberta, terminally ill patients are often admitted to hospital or hospice units during the final days of life because their informal caregivers are unable to manage their care. In order for patients to be able to remain at home until their death from cancer or until hospice admission is

desired, greater support must be provided to their family caregivers at this crucial time. Such support must be based on a thorough assessment of caregiver needs.

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National Cancer Institute of Canada (1998). Canadian Cancer Statistics 1998. Toronto, Canada.

Powers, J.S., & Burger, M.C. (1987). Terminal care preferences: Hospice placement and severity of disease. Public Health Reports, 102(4), 444-449.

Soukop, M., & Calman, K.C. (1977). Cancer patients: Where do they die - An analysis. Practitioner, 219, 883-889.

Appendix A

University of Alberta
Edmonton
Canada T6G 2G4

Faculty of Rehabilitation Medicine
Rehabilitation Research Centre
3-48 Corbett Hall
Director (403) 492-7856 Telephone (403) 492-2903
Fax (403) 492-1626

UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES, CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date: December 1997

Name(s) of Principal Investigator(s): Jacqueline Peden

Organization(s): University of Alberta

Department: Graduate Studies, Faculty of Nursing

Project Title: Needs of Family Caregivers Just Prior to the Cancer Patient's Admission to a Hospice to Die

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the patient information material and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval.

Sharon Warren

Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-021297-NSG

Appendix B

Capital Health

Regional Research Administration Office
CSB 9-122, 492-1372

Memorandum

NOTICE OF APPROVAL FOR PROPOSED RESEARCH
CAPITAL HEALTH AUTHORITY

Project Title:	Needs of Family Caregivers Just Prior to the Cancer Patient's Admission to a Hospice to Die
Project No.:	P-22
Investigator(s):	Jacqueline Peden
Department:	Faculty of Nursing
Division:	Graduate Studies
Address:	3rd Floor CSB
Phone/FAX:	455-6726

Supporting documents:

1)	Ethical Approval	December 1997
2)	Study Protocol	Received
3)	Funds:a) Source b) Type	Edna Minton Student Research Bursary Grant
4)	Overhead Negotiated	N/A
5)	Account #	U of A Faculty of Nursing
6)	Contract	N/A

Project Approved January 1998

THIS APPROVAL IS VALID FOR ONE YEAR

By

Title Maureen Bain, Manager
Regional Research Administration

Copies to: Department Chair/Health Sciences Faculty
Vicky Afacan, Acting Corporate Controller
Phil Heuchert, Manager Trust & Research Accounts

January 9, 1998

Appendix C

The CAPITAL CARE *Group*

#500, 9925 - 109 Street
Edmonton, Alberta T5K 2J8
Telephone: [403] 448-2400
Facsimile: [403] 429-2217

December 19, 1997

Ms. Jacqueline Peden
12260 St. Albert Trail
Edmonton, Alberta
T5L 4G6

Dear Ms. Peden:

The Capital Care *Group* Research and Evaluation Review Committee met on Monday, December 15, 1997 and reviewed your proposal entitled "Needs of Family Care Givers Just Prior to the Cancer Patient's Admission to a Hospice to Die." We were most impressed with your submission, and are pleased to grant approval for this much needed research.

We have approved the proposal pending receipt of the ethics approval by the Capital Health Authority Health Research Ethics Administrative Board.

We would appreciate a report on an annual basis and on completion of this study. Any changes in your protocol must be submitted to the Research and Evaluation Review Committee.

Sincerely,

Caroline Clark
Chair, Research and Evaluation Review Committee

CC/ml

l:\p\research

Appendix D

CARITAS HEALTH GROUP

16940 - 87 Avenue Edmonton, Alberta T5R 4H5 Tel. (403) 484-8811 Fax. (403) 930-5774

January 8, 1998

Ms. Jackie Peden
12260 St. Albert Trail
Edmonton, Alberta
T8N 4G6

Dear Ms. Peden:

Re: Needs of Family Caregivers just Prior to the Cancer Patient's Admission to a Hospice to Die

Thank you for submitting the above study, which has received ethical approval from the Health Research Ethics Administration Board, for administrative approval.

I am pleased to inform you that this study has been given administrative approval to be conducted within the Regional Palliative Care Program at Caritas. This approval is effective immediately.

We would appreciate a report to our Committee on completion of this project. It would also be appreciated if credit would be given to Caritas and its Research Steering Committee in publications when appropriate.

If you have any questions, please do not hesitate to contact me. I can be paged at the Grey Nuns Community Health Centre, or you may leave a message with the committee secretary, Peggy Morton, at 930-5924 (fax 930-5961).

Yours truly,

Ms. Brenda Waye
Manager, Corporate Services
Caritas Health Group

cc: Dr. Priscilla Koop
Faculty of Nursing

/pm

Appendix E

St. Joseph's
AUXILIARY HOSPITAL
SISTERS OF PROVIDENCE OF ST. VINCENT de PAUL

• 10707 - 29 Avenue, Edmonton, AB T6J 6W1 • • Phone (403) 430-9110 • Fax (403) 430-9777 •

January 19, 1998

Ms. Jacqueline Peden
12260 St. Albert Trail
Edmonton, AB
T5L 4G6

Dear Ms. Peden:

RE: RESEARCH PROPOSAL

I am pleased to inform you that your research proposal entitled **Needs of Family Caregivers Just Prior to the Cancer Patient's Admission to a Hospice to Die** was reviewed and approved by the Governing Board. Due to the number of research proposals that we have received, we recommended that your data collection start on January 1, 1998 to March 15, 1998.

We would appreciate a report on an annual basis and on completion of this study. Any changes in your protocol must be submitted to the Research and Evaluation Review Committee at St. Joseph's Auxiliary Hospital.

Sincerely,

Queenie Choo

Q. Choo
Director of Resident Care
QC/ik

Appendix F

Youville Home (Grey Nuns) of St. Albert

9 St. Vital Avenue
St. Albert, AB.
Canada T8N 1K1

Ph: (403) 460-6900
Fax: (403) 459-4139

February 10, 1998

Ms. Jacqueline Peden
12260 St. Albert Trail
Edmonton, Alberta
T5L 4G6

Dear Ms. Peden:

Re: Research Proposal

I am pleased to inform you that your research proposal entitled, "Needs of Family Caregivers just prior to the Cancer Patient's Admission to a Hospice to Die" has been approved.

I would appreciate a report on completion of this study. Please advise me of any changes in your protocol prior to said changes.

Sincerely,

Pat Cherry, R.N.
Director of Care Services

Appendix G

St. Joseph's
AUXILIARY HOSPITAL
SISTERS OF PROVIDENCE OF ST. VINCENT de PAUL

• 10707 - 29 Avenue, Edmonton, AB T6J 6W1 • • Phone (403) 430-9110 • Fax (403) 430-9777 •

March 25, 1998

Jacqueline Peden
12260 St Albert Trail
Edmonton, AB T5L 4G6

Dear Ms. Peden,

As per our discussion, St Joseph's ethics committee will grant you an extension to May 31, 1998 to recruit families for your study entitled **Needs of Family Caregivers Just Prior to the Cancer Patient's Admission to a Hospice to Die.** We are pleased to hear that arrangements have been made with other research studies that potentially are competing for the same subjects.

Sincerely,

Larissa Podilsky
Palliative Care Team Leader
St. Joseph's Auxiliary Hospital

Appendix H

CARITAS HEALTH GROUP

16940 - 87 Avenue Edmonton, Alberta T5R 4H5 Tel. (403) 484-8811 Fax. (403) 930-5774

May 6, 1998

Ms. Jacqueline Peden
Faculty of Graduate Studies and Research
University of Alberta
12260 - St. Albert Trail
Edmonton, Alberta
T5L 4G6

Dear Ms. Peden:

Re: Needs of Family Caregivers just prior to the Cancer Patient's Admission to a Hospice to Die

Thank you for your letter of May 5, 1998 requesting approval of a change in the method of recruitment for this study. The method of providing an information letter through the Unit Clerk to the family members should the nurse consultant from the Regional Consult Team be unsuccessful in contacting the family is quite acceptable.

I am pleased to inform you that this change to the protocol has the approval of the Caritas Research Steering Committee.

If you have any questions, please do not hesitate to contact me. I can be paged at the Grey Nuns C.H. & H.C., or you can leave a message with the Committee secretary, Ms. Peggy Morton, at 930-5924 or 930-5961.

Yours sincerely,

G.F. MacDonald, M.D., FRCP(C)
Chair, Caritas Research Steering Committee

/pm

Appendix I

***Research Study*: Needs of family caregivers just prior to the cancer patients admission to a palliative continuing care unit**

***Researcher*:** Jackie Peden, RN, MN (Candidate)
Faculty of Graduate Studies, University of Alberta

I am conducting a research study about the **needs of family caregivers just prior to the admission of their family member to a continuing care facility with designated palliative care beds**. The purpose of this study is to identify the needs of family caregivers who are unable to keep their family member at home to die. I plan to interview family caregivers from ***February 1, 1998 to May 31, 1998*** or until ***30 participants*** are obtained.

To be included in this study ***the primary family caregiver must be 18 years or older*** and ***able to understand English***. The advanced ***cancer patient*** of the family caregiver ***must be admitted into the hospice from home***. I ask that you contact the family caregiver ***within the first week of the cancer patient's admission*** to the palliative continuing care unit to determine if he or she is interested in being part of this research study.

If the family caregiver is interested in being part of the study I ask that you contact me. My home telephone number is: **455-6726**, if I am not at home please leave a message and I will return your call as soon as possible.

Thank-you for your involvement and support of this study.

Appendix J

Needs of family caregivers just prior to the cancer patients admission to a hospice

Researcher: Jackie Peden, RN, MN (Candidate), Faculty of Graduate Studies, University of Alberta

I am conducting research about what it is like to be a caregiver. The purpose of this study is to identify your needs when your family member was at home. I am interested to know how well these needs were met. I am interested in the time period when you felt your family member could best be looked after in a hospice setting.

There are two questionnaires to complete. The first questionnaire asks for basic information about you and your family member. The second questionnaire asks you about needs that were important to you when you were a caregiver. My visit with you should take less than one hour.

A risk of participating in the study is that answering the questions could make you sad. A benefit of this study is that it may provide an opportunity to share your story. The results of this study will increase understanding of family caregiver needs. The findings may improve the future support given to family caregivers during this time.

You may refuse to participate or withdraw from this study. You do not have to give me a reason. If you refuse to participate or withdraw from this study it will not affect your family member's care.

You will not put your name on the questionnaires. Your questionnaires will be given a number. The list which matches your name to the number will be kept in a locked drawer. I will be the only person with a key to this drawer. The list will be destroyed after the study is completed. The answers you give on the needs questionnaire will be sent to the researcher who developed this tool but your identity will not be revealed. Information about caregiver needs may be shared with other health care workers but your identity will not be revealed. Information may be published, presented at a conference, or used in future research but your identity will not be revealed.

If you are interested in being in this study please tell the person who is explaining the study to you. She or he will contact me. I will call you to answer any further questions. If you are still interested in being in the study I will make an appointment to visit you. I can visit you while you are visiting your family member on the palliative unit, in your home, or a location of your choice.

If you have any concerns about any aspect of this study, you may contact the Patient Concerns Office of the Capital Health Authority at 474-8892. This office has no affiliation with study investigators.

Appendix K

Consent Form

Title of Project: Needs of family caregivers just prior to the cancer patients admission to a hospice

Principal Investigator: Jacqueline Peden, RN, MN (Candidate)
Faculty of Graduate Studies, University of Alberta
455-6726

Thesis Supervisor: Dr. Priscilla Koop, Assistant Professor
Faculty of Nursing
492-2962

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and risks involved in taking part in this research study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from this study at any time? You do not have to give a reason and it will not affect your family member's care. Yes

No

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records? Yes No

This study was explained to me by: _____

I agree to take part in this study:

_____ _____ _____

Signature of Research Participant Date Witness

_____ _____

Printed Name Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____

Signature of Investigator Date

Appendix L

Information About You And Your Family Member

Subject ID number _____

Please respond to the following questions by writing in or circling the correct answer.

Your Age _____ **Family Member's Age** _____

Your Gender
Female Male

Family Member's Gender
Female Male

What is your relationship to the family member who was admitted to the hospice?
Wife Husband
Daughter Son
Daughter-in-law Son-in -law
Friend Other_____

How long were you the caregiver for your family member?_____

Combined Yearly Income of Household
$10,000 or Less $10,100 to $20,000
$20,100 to $30,000 $30,100 to $40,000
$40,100 to $50,000 $50,100 or more

Does your family member have private supplemental health insurance?
Yes No

Your highest level of education?
Below Grade 12 Grade 12 Post Secondary

How would you describe your health?
Poor Fair Good Excellent

Did you live in the same house as your family member who is ill?
Yes No

Was it necessary to move into your family member's home to provide care?
Yes No

Were you the only family caregiver?
Yes No

If no, who else provided care?_____

_____

Did your work status change as a result of your family member's illness?
Yes No

Did your financial status change as a result of your family member's illness?
Yes No

Did finances affect your ability to provide care for your family member at home?
Yes No
If yes, explain_____

_____

What type of cancer does your family member have?_____

_____

How long has your family member been ill?_____

_____

Did you want your family member to die at home?
Yes No

If yes, what changed your mind?

_____

_____

_____

If no, why not?

_____

_____

_____

Did your family member want to die at home?
Yes No

If yes, what changed his/her mind?

_____

_____

_____

If no, why not?

_____

_____

_____

What services or support would have helped you keep your family member at home?_____

_____

_____

Do you have any other caregiver needs that were not reflected on this survey? If yes, please list them._____

_____

_____

Appendix M

HOME CAREGIVER NEED SURVEY

DIRECTIONS:

The following list of needs was identified by caregivers of patients at home. To identify your needs as a caregiver of a patient at home, please:

1. Read the first need statement.
2. If the statement does not apply to you, check the box under **"DOES NOT APPLY TO ME"**
3. If the statement does apply to you,

PLEASE EVALUATE EACH NEED STATEMENT IN TWO WAYS:

First, ask yourself **"How important was this need for you?"**, during the last week of my family member's life. Then beside that need statement, please check a box between "very important" and "not important" to show how important that need was for you during the last week of your family member's life.

Second, ask yourself **"How satisfied was this need for you?**, during the last week of my family member's life? Then check one box between 'not satisfied" to show how satisfied that need was for you.

Follow this procedure for each item. Don't spend too much time on your answers; your first thought is probably the best. Please answer every statement and be sure to mark **TWO BOXES** for each statement that applies to you.

EXAMPLE:	**DOES NOT APPLY TO ME**	**HOW IMPORTANT WAS THIS NEED FOR YOU?** Please check a box: Not Important … Very Important	**HOW SATISIFED WAS THIS NEED FOR YOU?** Please check a box: Not Satisfied … Very Satisfied
Support from my neighbors		X	X

This example would indicate a need which was very important, but not satisfied.

I. NEEDS INVOLVING INFORMATION

	DOES NOT APPLY TO ME	**HOW IMPORTANT WAS THIS NEED FOR YOU?** Please check a box: Not Important … Very Important	**HOW SATISIFED WAS THIS NEED FOR YOU?** Please check a box: Not Satisfied … Very Satisfied
1. Information about medications - effects and schedules			
2. Information about treatment side effects			

	DOES NOT APPLY TO ME	HOW IMPORTANT WAS THIS NEED FOR YOU? Please check a box: Not Important 1 2 3 4 5 6 7 Very Important	HOW SATISIFED WAS THIS NEED FOR YOU? Please check a box: Not Satisfied 1 2 3 4 5 6 7 Very Satisfied
3. Information about the underlying reasons for symptoms			
4. Information about what symptoms to expect			
5. Access to physicians			
6. Honest and updated information			
7. Information about the physical needs of my patient			
8. Information about therapies			
9. Information about drugs			
10. A trusting relationship with my patient			
11. Information about the type and extent of my patient's illness			
12. Information on how to give medications			
13. Ways to inform children			
14. Ways to cope with role changes			

II. NEEDS INVOLVING YOUR HOUSEHOLD

1. Help with errands			
2. Help with my housework			
3. Help with transportation			

	DOES NOT APPLY TO ME	HOW IMPORTANT WAS THIS NEED FOR YOU? Please check a box Not Important → Very Important	HOW SATISIFED WAS THIS NEED FOR YOU? Please check a box Not Satisfied → Very Satisfied
4. Help with my yard work			
5. A caregiver hotline			
6. Non – professional help with my patient's physical care			
7. Time for myself – away from the house			
8. Help continuing my children's activities			
9. A caregiver support group for me			
10. Places to go for professional counseling			
11. Help with baby sitting			
12. Information about community resources			

III. PATIENT CARE NEEDS

1. Ways to help my patient maintain some independence		
2. Ways to keep my patient comfortable		
3. Information about which liquids are best for my patient		
4. Ways to provide my patient with adequate nutrition		
5. Methods of pain control		
6. Activities that will make my patient feel purposeful		

	DOES NOT APPLY TO ME	HOW IMPORTANT WAS THIS NEED FOR YOU? Please check a box Not Important → Very Important								HOW SATISIFED WAS THIS NEED FOR YOU? Please check a box Not Satisfied → Very Satisfied							
7. Ways to deal with my patient's decreased energy																	
8. Information about how to get my patient to eat																	
9. Ways to dress my patient comfortably																	
10. Equipment to help with patient care																	
11. Ways to reassure my patient																	
12. Professional help with my patient's physical care																	
13. Ways to improve my patient's appearance																	
14. Ways of coping with my patient's diagnosis																	
15. Not leaving my patient alone																	
16. Home visits by professionals to check my patient																	

IV. PERSONAL NEEDS

1. Time for my personal needs																	
2. Time to rest																	
3. Maintaining my own health																	
4. Adequate sleep																	
5. Someone with whom to talk																	

	DOES NOT APPLY TO ME	HOW IMPORTANT WAS THIS NEED FOR YOU? Please check a box: Not Important 1 2 3 4 5 6 7 Very Important	HOW SATISIFED WAS THIS NEED FOR YOU? Please check a box: Not Satisfied 1 2 3 4 5 6 7 Very Satisfied
6. Understanding from my patient			
7. Appreciation from my patient			
8. Continuing my social activities			
9. Support from my family			
10. Support from my friends			
11. Caring and interested professionals			

V. SPIRITUAL NEEDS

1. Personal prayer for strength			
2. Prayers from others			
3. Support from my church			
4. A strong faith in God			
5. Clergy with whom to talk			
6. Hope for the future			

VI. PSYCHOLOGICAL NEEDS

1. Ways to deal with the unpredictability of the future			
2. Information about death and dying			

	DOES NOT APPLY TO ME	HOW IMPORTANT WAS THIS NEED FOR YOU? Please check a box Not Important → Very Important								HOW SATISIFED WAS THIS NEED FOR YOU? Please check a box Not Satisfied → Very Satisfied							
3. Help dealing with my fears																	
4. Ways to deal with my depression																	
5. Ways to discuss death with my patient																	
6. Information about what to expect in the future																	
7. Ways to deal with my anger																	
8. Information about funeral planning																	
9. Ways to deal with my guilt feelings																	
10. Information on hospice care																	
11. Information about legal matters																	
12. Ways to be more patient and tolerant																	
13. Ways to resolve unfinished business with my patient																	
14. Ways to maintain a normal family life																	
15. Help with financial matters																	
16. Ways to better communicate with my patient																	
17. Ways of coping with my loneliness																	
18. Ways to combat fatigue																	

	DOES NOT APPLY TO ME	HOW IMPORTANT WAS THIS NEED FOR YOU? Please check a box Not Important → Very Important								HOW SATISIFED WAS THIS NEED FOR YOU? Please check a box Not Satisfied → Very Satisfied							
19. Methods to decrease my stress																	
20. Ways to encourage my patient																	
21. Feedback that I am giving my patient proper care																	
22. Bereavement follow up																	
23. Ways to inform family																	
24. Information about my patient's psychological needs																	
25. Classes on giving physical care to my patient																	
26. A patient support group for my patient																	
27. Financial help																	
28. Ways to deal with my sexual needs																	
29. Information about activities and exercises for my patient																	
30. Help with understanding insurance forms																	

Appendix N

School of Nursing

University of Missouri-Kansas City
2220 Holmes Street
Kansas City, Missouri 64108-2676

Jackie Peden
12260 St. Albert Trail
Edmonton, Alberta
T5L4G6

UMKC

February 7, 1997

Dear Jackie,

Thank you for your interest in the Home Caregiver Need Survey! Good luck with your graduate work and your research on the needs of family caregivers of terminal patients. As I told you I am also a Hospice nurse, so I know how important it is for all of us to assess needs and develop interventions for family caregivers of dying patients.

Office of the Dean
816 235-1700
Academic Programs
816 235-1709
Advancement Office
816 235-1775
Business Office
816 235-1732
Distance Education
816 235-1710
Student Services
816 235-1740
Fax
816 235-1701

Outreach Sites:
Joplin, MO
417 625-9322
St. Joseph, MO
816 271-5914

Enclosed you will find a "generisized" copy of the Home Caregiver Need Survey. (The original one was designed only for caregivers of cancer patients at home.) Five one-word changes were made so the instrument could be used with caregivers of <u>any</u> population at home. I used it with caregivers of patients with AIDS and got high reliability and validity (see abstracts enclosed). Over 50 others, in 4 countries, have used it with caregivers of cancer, chronically ill, Alzheimer's, and Hospice patients with good reliability.

Enclosed you will find a couple copies of the HCNS. I also included copies of the articles I've published. I also enclosed some abstracts that will give you other reliability and validity information. The instrument development and the AIDS study have not been published yet.

You have my permission to use the tool or any part of it in your practice or research. Each section (sub-scale) has it's own reliability so can be used independently.

The HCNS works really well for a one-on-one (nurse and family caregiver) because, on admission to service the nurse can eye-ball the completed HCNS to see when 2 "X's" are close together for an item--which indicates a need that is <u>both important and not satisfied</u>. Interventions to meet the caregiver's identified needs is then built into the care plan. Then on future visits, nurses can take additional copies of the HCNS and highlight the need items that were important and not satisfied for this caregiver and assess caregivers on a continuous basis to see if the team is making progress on meeting the caregiver's unmet needs. Going over just the highlighted items is time-effective, but if the family is on service a long time, you may have to give them the complete HCNS every few months because their needs change as their patient's needs change.

I am very happy for you to use the HCNS, I only ask that when you are done with your study, you send me a copy (diskette) or E-mail of your raw data including HCNS, demographics, anything else you decide to collect, and your results. Also, a copy of your publication would be nice. That will help me do another factor analysis on a secondary analysis of my raw data and many others, like you. I use Mircrosoft Word, but I have most converters. You can send it on whatever software you use, just mark the diskette so I know what software you used. When I do the analysis including your data, I will give you recognition in the published article.

Let me know if I can be of <u>any</u> further help. Call me anytime: H 913-432-6325, W 816-235-1720, or E-mail hilemanj@smptgate.umkc.edu. Good luck!

Sincerely,

Judy Hileman

Judy Willis Hileman, ARNP, PhD; Assistant Professor,
Coordinator Distance Education UMKC School of Nursing

an equal opportunity institution

Appendix O

Judy Hileman, 03:34 PM 10/15/97, Permission and Blessing!!

Date: Wed, 15 Oct 97 15:34:21 CDT
From: "Judy Hileman" <HilemanJ@smtpgate.umkc.edu>
Encoding: 1 Text
To: jpeden@maildrop.srv.ualberta.ca
Subject: Permission and Blessing!!

Jackie, No problem!! Use, alter, and enjoy the HCNS! I'm in the process of trying to cut it down so it won't be so long! Good luck with your retrospective study. Let me know what you find out! Feel free to contact me again, if I can be of help or if you need a formal letter of permission. Sincerely, Dr. Judy Hileman